

# **Autism Program Summary**

## **Division of Developmental Disabilities**

### **July 2007 – June 2008**

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#### **Introduction**

This program summary will highlight programs and services in which the Division of Developmental Disabilities participated or funded during the time frame of July 2007 through June 2008. The information and data is specific to people, both children and adults, who have Autism Spectrum Disorders (ASDs).

As expected, there was an increase in the number of people with ASD enrolled with the Division of DD. Nearly 6,400 children and adults with ASD are presently enrolled with Division of DD compared to almost 5,400 people enrolled in a previous twelve-month period. Each of these children and adults has a service coordinator, and some are receiving services such as respite, personal assistance, applied behavior analysis, or supported living. About 1,400 of the children and adults who have a service coordinator are waiting for services.

Division of DD's testimony provided to the Blue Ribbon Panel reflected that more than \$44 million in service dollars was spent by Division of DD on behalf of people with ASDs during a twelve-month period ending May 2007. The next year (ending in June 2008) funds spent on services increased to approximately \$56 million, a 27% increase over the previous counting period. Funding targeted for the Missouri Autism Projects, the Ozark Center and the Centers of Excellence is in addition to the \$56 million spent on services.

The funding for services will increase in fiscal year 2009, as described later in this summary. And, enrollment with Division of DD will very likely increase throughout this next year.

An accepted measure of prevalence from the national Centers for Disease Control is that ASD affects one in every 150 children. At this point, nearly all of us have a personal connection with someone who has an ASD—perhaps a co-worker, a friend, or a member of our family.

#### **Missouri's 2007 Blue Ribbon Panel on Autism**

April 2007 heralded the announcement by Senator Michael Gibbons of Missouri's first "Blue Ribbon Panel on Autism." The Blue Ribbon Panel's task was to define the state of autism in Missouri. The 16-member Blue Ribbon Panel was comprised of parents, a grandparent, physicians, educators, service providers, and state agency representatives. Five hearings were held in Missouri with hundreds of family members, physicians, and autism specialists attending as well as offering testimony. The chairperson of Missouri's Autism Advisory Committee, Nikki Straw, and other members of the regional Autism Advisory Committees enjoyed representation on the panel offering their perspective as family members who understand the impact of autism.

After reviewing Missouri's systems of care, educational programs, existing diagnostic clinics, and insurance coverage, the panel developed 36 recommendations for improving the quality of life for individuals with autism and their families.

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Issued in December 2008, the “Missouri’s Blue Ribbon Report” acknowledges the strong foundation in Missouri upon which to base the comprehensive recommendations contained therein. The Blue Ribbon Report can be viewed at <http://www.senate.mo.gov/autism/autism2007.pdf>.

## Legislation

### Missouri Commission on Autism Spectrum Disorders

June 23, 2008, was another historic day in Missouri for the autism community. Lt. Governor Peter Kinder signed Senate Bill 768 creating the “Missouri Commission on Autism Spectrum Disorders” to be housed within the Department of Mental Health. The bill is effective August 28.

The Commission will have 24 members, including 4 members of the state’s general assembly and 7 ex officio representatives from various state departments. The 13 remaining members are appointed by the governor with the advice and consent of the senate, and must include 2 parents of people who have autism; 2 persons who have an autism spectrum disorder; and providers from the educational, therapeutic, and healthcare fields.

The Commission’s primary charge is to develop a comprehensive statewide plan for an integrated system of training, treatment, and services for individuals of all ages with autism spectrum disorders.

### Office of Autism Services

Senate Bill 768 also establishes the “Office of Autism Services,” and charges that office with 1) leadership in program development for children and adults with autism spectrum disorders, 2) establishment of program standards and 3) coordination of program capacity.

The OAS is housed within the Division of DD. One goal of the OAS is to increase the focus and knowledge base within the existing system of care offered by Division of DD. Thus, people with developmental disabilities including ASDs will continue to enroll with Division of DD through the eleven Regional Offices, receive primary assistance through their service coordinator, and authorization of services through the Division of DD budget appropriations.

As specifically required by Senate Bill 768, the OAS will provide technical and administrative support to the 24-member Commission on Autism. In anticipation of the passage of Senate Bill 768, the Division assigned 2 staff in March 2008 to lay the framework for the Office of Autism Services.

The creation of the “Commission on Autism Spectrum Disorders” and the “Office of Autism Services” were recommendations 1 and 3 in the Blue Ribbon Report. To view the complete text of Senate Bill 768, see <http://www.senate.mo.gov/08info/pdf-bill/tat/SB768.pdf>.

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## Fiscal Year 2008 Appropriations

### Autism Centers of Excellence

\$2.4 million was appropriated to reduce wait times for clinical appointments for the timely diagnosis of ASDs in three regions of Missouri. These clinics received the funding:

1. Developmental and Behavioral Sciences Section, Children's Mercy Hospitals and Clinics, Kansas City. See <http://www.childrensmercy.org>
2. University of Missouri Thompson Center for Autism and Neurodevelopmental Disorders, Columbia. See <http://thompsoncenter.missouri.edu>
3. Knights of Columbus Developmental Center at Cardinal Glennon Medical Center, St. Louis. See <http://www.cardinalglennon.com>

The Centers of Excellence have as their primary goals:

- Reducing the amount of time children and families wait before receiving an appropriate diagnosis;
- Providing critical diagnostic information to families in a timely manner, making necessary referrals for services; and
- Strengthening training efforts within the clinics and their complementary community-based service providers.

According to the centers' reports, each center has successfully reduced the time families wait for a diagnostic appointment, adding healthcare professionals to their staff and effectively utilizing the new appropriations. All children referred to the centers receive a full medical evaluation, testing or referrals even though the final diagnosis may be a developmental disability other than an autism spectrum disorder.

The Office of Autism Services receives quarterly and annual program updates from each of the three Centers of Excellence. The OAS also coordinates bi-monthly program reviews for the centers as a forum to discuss and share best practices.

### Ozark Center

The Ozark Center, affiliated with Freeman Health Systems, received \$500,000 for an innovative applied behavior analysis program housed in the Joplin, Missouri, office. A child's therapy team consists of the family, caregivers, a certified behavior analyst, and a speech and language pathologist. The program began October 2007 and serves children up to age six. This is a new service in southwestern Missouri and helps fill a critical gap in available services for families with young children.

### Missouri's Autism Projects

In fiscal year 2008, the appropriation for services targeted for the regional autism projects increased by \$1 million; a matching amount is appropriated in the 2009 budget. The projects' genesis dates to the early 1990's. Now established in state regulation, there are 5 regional parent committees that advise and recommend on matters such as autism-related policy, funding models and service providers. Each of the committees has representation on the state level "Missouri Advisory Committee on Autism."

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A single-provider network offers services in three of the project's regions and has helped thousands of families throughout the years. Various other providers offer services in the eastern and north-western project areas with providers selected by families. In addition, an applied behavioral analysis program is offered in southeastern Missouri.

### **Model Programs**

#### Mid-Missouri Autism Rapid Response Initiative

The Mid-Missouri Autism Rapid Response Initiative, funded by Division of DD, is a pilot in Boone County responding to a recognized need for families to receive core, credible information in a timely way. This group has grown from 6 participants to almost 50, including parents, public and private agencies, and service providers.

Rapid Response aims to 1) decrease wait times for diagnosis and interventions; 2) provide family members with education and supports during the diagnostic process and immediately afterwards; and 3) increase the number of children who are routinely screened for Autism Spectrum Disorders.

The Rapid Response team can claim a number of accomplishments:

- Recruited a "Family Support Specialist" at the MU-Thompson Center to link families with community-based services and supports after receiving a diagnosis;
- Developed and distributed over 2,000 "Could My Child Have Autism?" brochures; and
- Developed and distributed over 2,000 "Help for You and Your Child with Autism" brochures in central Missouri.

The brochure entitled "Could My Child Have Autism?" is posted on Division of DD's website and can be downloaded by those interested in distributing or displaying the brochure. See [http://www.dmh.mo.gov/Division of DD/progs/autism](http://www.dmh.mo.gov/Division%20of%20DD/progs/autism) to view the brochure.

Testimony regarding the Rapid Response Initiative was presented to the Missouri Blue Ribbon Panel on Autism as recommendation number 20. As a result, an appropriation of \$180,000 was included in Division of DD's fiscal year 2009 budget.

#### Intensive Behavior Support Pilot

The Intensive Behavior Support Pilot project is a behavioral consultation service. The pilot aims to improve outcomes for individuals with autism spectrum disorders (ASDs) by empowering the family and caregivers to deal with challenging behavior that is unusual in intensity or complexity. The service is guided by a highly credentialed and experienced behavioral therapist.

The service begins with an evaluation and assessment of the individual's needs via a comprehensive review of all records, treatment interventions, and medical records. Then the behavioral therapist identifies the function of behavior in a clinical setting, developing and testing the effectiveness of an individualized, behavioral intervention plan. A key component of this pilot is moving the center-based therapy to the family's home and the child's school. The therapist helps the parents, educators, and other professionals learn and apply the strategies at home and school.

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This comprehensive and coordinated approach in assisting families is not well reimbursed by traditional funding streams so is funded by the Division of DD System Transformation Grant.

### Federal Financial Participation Exploration Task Force

In March 2008, Division of DD convened the “Federal Financial Participation Exploration Task Force,” in response to recommendation number 18 of the Blue Ribbon Report. Consequently, the Division is exploring an autism-specific waiver with services specific to people with ASD. If approved, this waiver will be the 4<sup>th</sup> waiver administered by the Division, all of which offer services to people with developmental disabilities including ASDs. For more information on the existing waivers see the fact sheet at:

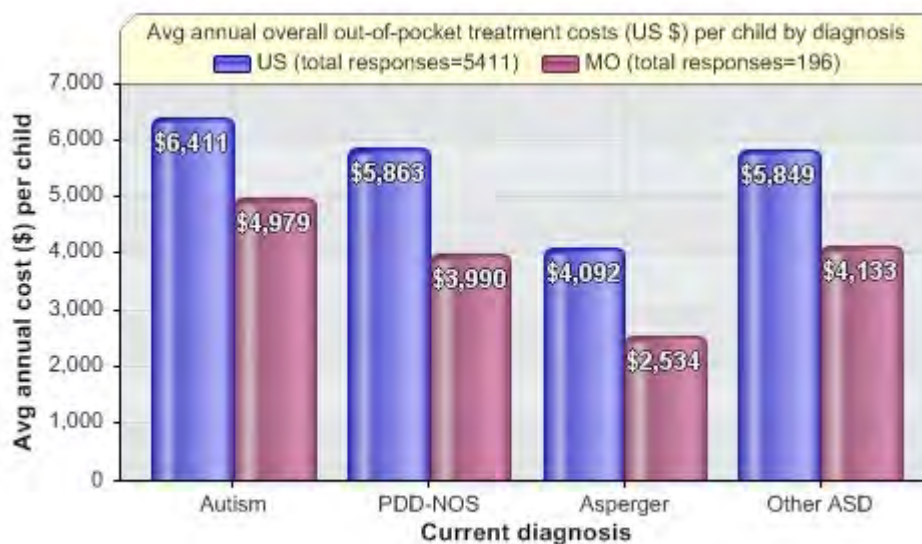
[http://www.dmh.mo.gov/Division of DD/progs/waiver/factsheet.htm](http://www.dmh.mo.gov/Division%20of%20DD/progs/waiver/factsheet.htm).

### **Missouri as a National Partner**

#### Interactive Autism Network

The Division of DD, MU-Thompson Center, and the Kennedy Krieger Institute jointly developed a state-level model for accessing the Interactive Autism Network (IAN) data. As a result of this collaboration, the Interactive Autism Network’s “State Stats” was launched nationwide June 30.

The data and information available from IAN and “State Stats” can be used by administrators and legislators who develop and make decisions about public health policy. The charts and graphs available on StateStats feature six data summaries. One chart displays the distribution of Autism Spectrum Disorders among Missouri children whose families have enrolled in the voluntary registry. Another summary underscores the family impact of autism, displaying average out-of-pocket treatment expenses incurred by families with ASD:



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"Avg annual overall out-of-pocket treatment costs (US \$) per child by diagnosis" Chart. Kennedy Krieger Institute. Interactive Autism Network StateStats. Retrieved August 8, 2008 [http://www.iancommunity.org/cs/for\\_researchers/ian\\_statestats](http://www.iancommunity.org/cs/for_researchers/ian_statestats), Data current as of August 8, 2008.

The Interactive Autism Network, a project funded by Autism Speaks and developed by Kennedy Krieger Institute, was created with a primary goal to accelerate the pace of autism research. To research resources or enroll in the Interactive Autism Network, view <http://www.ianproject.org>.

## Education and Outreach

A priority of the Division of DD and the OAS is increasing public awareness and general knowledge about developmental disabilities and ASDs. Outreach this year included attendance at a 4-state summit hosted by the Centers of Disease Control outlining its "Learn the Signs, Act Early" campaign. This summit was part of the CDC's awareness campaign to educate parents about childhood development, including early warning signs of autism and other developmental disabilities. Free resource materials can be ordered or downloaded at the web-site:

<http://www.cdc.gov/ncbddd/autism/ActEarly/ccp/downloadmaterials.html>

The Division was one of several states invited to present this year at the National Association of Developmental Disabilities Directors' mid-year meeting, hosted in partnership with the Autism Society of America. In addition, the Office of Autism staff made presentations for various organizations and media events:

- Missouri Association of County Developmental Disabilities Boards
- Missouri chapter of American Network of Community Options and Resources
- Columbia Missourian "Centennial" Issue
- Department of Mental Health's "Mental Health Moments" with JCTV
- Missouri's Mental Health Commission, February and June meetings
- Coalition of Community Mental Health Centers
- Columbia chapter of Missouri's League of Women Voters, KCAT, and MU Thompson Center

## Missouri's Challenges

Families continue to bear the emotional and financial weight for treating their loved ones. For example, there are media reports of families spending between \$25,000 and \$100,000 annually for behavior therapies such as applied behavior analysis. In Missouri specifically, average out-of-pocket costs for a variety of treatments totaled nearly \$5,000 per child each year (see IANproject.org, State Stats). Many adults with ASD are not able to reach their potential, or to lead the lives they wish to because of a lack understanding about supports that are needed as well as insufficient services available to help them.

While Missouri has a strong history of autism advocacy and services, its citizens face a number of challenges:

- Improving collaboration at the individual, local and state level;
- Balancing autism diagnostic programs with services available at home, in school or in the community;



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- Developing standards for autism diagnosis, assessment and treatment; and
- Continuing the present momentum with sufficient human and financial capital.

### On the Horizon

Over \$3 million was appropriated for services provided through the Division of DD beginning in July 2009. During the current fiscal year, the Division is seeking approval for an autism-specific waiver, drafting new service definitions to strengthen its response to autism.

The Southeast Missouri Autism Diagnosis and Treatment Center is taking shape with funding from the Lewis and Clark Initiative for a center-based program, with \$480,000 appropriated for services. The center will be located on the campus of Southeast Missouri State University, Cape Girardeau.

Burrell Behavioral Health Center in Springfield, associated with Cox Health System, received \$100,000 to enhance services to children with autism. According to its web-site, Burrell's mission is to help people maximize their potential offering behavioral services for children, adolescents and families as well as adults and seniors.

The expansion of the Mid-Missouri Autism Rapid Response Initiative will fund a "Family Navigation Guide," a pamphlet aimed at helping individuals and families navigate the various systems of care in Missouri. In addition, "Family Resource Specialists" will be housed at each Autism Center of Excellence, linking families with appropriate resources in their communities.

Judevine Center for Autism continues its commitment to professional credentialing and capacity building by sponsoring a cohort of Master's level students at Southern Illinois University-Carbondale during the fall semester. These students will be completing coursework preparing them for certification as "Board Certified Behavior Analysts."

A coordinated training effort between the Department of Elementary and Secondary Education, MU Thompson Center, University of Missouri Extension, and the Office of Autism is scheduled for October 24 using iTV to broadcast live training sessions in twelve cities. Additional community partners will be invited in the future to form a more comprehensive, coordinated training network in response to Blue Ribbon Panel recommendation 32.

Missourians can expect to see the first appointments to the Commission on Autism, and attend the first Commission meetings hosted by the Department of Mental Health.

For these accomplishments, much credit must be given to individuals and family members who share their personal stories in order to inform and educate. Much credit must also be given to organizations such as the Greater Kansas City Autism Alliance, the Missouri Autism Coalition, Autism Speaks and MO-FEAT for their resource directories and equally resourceful staff and volunteers. Finally, we give credit to the many concerned citizens, government officials and legislators, and service providers who have joined hands with the autism community to improve the lives of people who have Autism Spectrum Disorders.

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